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ABSTRACT

The workbook presents a model of care for children with severe medical involvement that features the professional care manager. Three phases in planning for home/community discharge are identified: identification of the candidate for in-home care; identification of specific objectives, service providers, funding sources, etc.; and full implementation of the home care plan. Roles of the parents, primary physician, care manager, interdisciplinary team, and community support services personnel in the transition from hospital to home are examined. A section on planning for discharge and home covers the discharge plan and the home care plan, and includes sample checklists for determining the home's physical facility standards. The final section addresses the organizational system of community resources. (CL)

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WORKBOOK SERIES FOR PROVIDING SERVICES TO

CHILDREN WITH HANDICAPS AND THEIR FAMILIES

GETTING CHILDREN HOME: HOSPITAL TO COMMUNITY

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University of Illinois
Division of Services for Crippled Children

Prepared by Georgetown University Child Development Center for the Division of Maternal and Child Health under Grant #MCJ-113368-01-1, Project Director, Phyllis R. Magrab, Ph.D.

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TO THE PARENTS AND CARE MANAGERS

Fortunately, times and attitudes change in health care. For decades the pediatric community believed that severely disabled children could be cared for only in an acute-care hospital or in an institution. Now we have realized that the least restrictive environment, usually the child's own home, is the best locale for the child. This workbook, intended for parents, care managers, and all those dedicated to health care is about **Getting Children Home: Hospital to Community.**

Until recently many severely medically involved "high tech" children were "institutional cases" because of their highly specialized medical needs. The 1980s have made the health-care professionals increasingly aware of the plight of severely handicapped youngsters and their families. The term "least restrictive environment," once thought to be the concern only of educators of handicapped children, is the concern of the pediatric community as well. The conceptual model presented in this workbook is an effort to provide a map for the journey from primary diagnosis to in-home care. The pilot for this journey is a professional care manager who has learned the critical components of service planning and community involvement. The manager can assist the parents to participate in planning for the child.

The journey from the primary diagnosis to home can be long and tedious--yet distinguished by landmarks only the child and his family can truly appreciate. This workbook is a roadmap and a time schedule for the journey. The first section outlines the three phases from initial planning to the placement in the home. The next section outlines the roles of various guides and pilots of the journey. The third section details the actual map, or discharge plan and home care plan. The final section centers upon using the community resources--the gas stations and repair shops--which help during the trip and especially after the journey is complete and the child is at home. Throughout, the workbook incorporates checklists, charts, diagrams, and sample documents to aid you--the parents/care managers.

SECTION I

THE THREE PHASES IN PLANNING FOR HOME/COMMUNITY DISCHARGE

There are three consecutive and distinct phases in the journey; each takes the child and family closer to a successful return home. Each phase can be understood in terms of:

- Its goal
- The key players and their roles
- The major activities needed for successful completion of that phase

Phase I

The first phase consists of appropriate identification of the candidate for in-home care. The assessment of the child and his/her total environment should ordinarily include the child's **Parents**, the primary medical specialist or attending **Physician**, the **Interdisciplinary Team**, and the **Care Manager**.

GOAL: Evaluation of the candidate for home care

Phase II

After the child has been identified as a candidate for discharge from the medical (institutional) facility for in-home care, the task is to identify specific objectives, service providers, funding sources, etc., necessary to realize the child's in-home placement. This phase requires careful analysis by the **Care Manager** and the child's **Parents**, and all plans must be double-checked to assure that all objectives are met before the child's discharge. During this phase, the **Discharge Plan** is developed and implemented and the **Home Care Plan** is designed.

GOAL: Drawing up Discharge and Home Care Plans

> This phase is crucial in planning for the discharge and home care. The major conceptualization, scheduling, and analysis must take place in this phase **BEFORE** the child comes home.

Phase III

The final phase begins as soon as the child is discharged from the medical facility to a family home. Then the **Home Care Plan** is fully implemented, services to the child and his/her family are in place, and maintenance at home begins.

GOAL: Discharge from the institution and implementing the **Home Care Plan**

SECTION II

THE KEY ROLES

The journey from hospital to home requires the interaction of many people. While "the crew" varies with each child, several key positions will always need to be filled--and their tasks assigned--to make the trip home a pleasant voyage. The major participants are the child's **Parents** (or legal guardian), the primary **Physician**, the **Care Manager**, the **Interdisciplinary Team**, and the **Community Support Services** personnel.

The Parents

The definition of **Parent** includes mother and/or father, or the child's court-appointed legal guardian--the person who has legal responsibility for the child's care, support, and protection. In most cases, the child's **Parents** will be actively involved in the Care Plan, but many severely disabled children are under the guardianship of public and private welfare agencies because of the inability or unwillingness of the child's parents to assume the responsibility for the child's care and support. In such cases the child will probably have a social worker representing the guardianship agency. This agency must be involved in approving and coordinating the child's discharge.

During Phase I, the **Parents** are both participants and subjects in the assessment process. Professionals will evaluate the **Parents'** interest and overall ability to care full-time for their child at home. The limit of the focus of attention in this phase should not be the stability of the child's condition or the feasibility of maintaining the child outside a specialized facility. The child's family must participate in determining their ability to cope with the many adjustments of full-time caring for the child at home.

Along with the **Care Manager**, the **Parents** must be actively involved during Phase II. They will help to identify the needed services and supports necessary to achieve in-home care. The parents must be involved not only in the development of the **Home Care Plan**, but in its implementation. When the child enters the home, Phase III, the **Parents** begin to assume more and more responsibility for the care of the child.

GUIDELINES FOR PARENTS*

1. Get as much information as you can about the child's disability. Talk to professionals; search for the most recent books, brochures, and articles. In the interest of your child, you are on your way to becoming an expert.
2. Ask questions about where your child's condition is NOW. Avoid being discouraged. Remember that there are changes and advances in research, services, and legislation.
3. Keep a written record of all conversations and information given to you by experts.
4. Think of how you will budget your time to meet the needs of your child, your spouse, your other children, your extended family, your friends, and YOURSELF.
5. Persuade gently. You are your child's primary advocate. Remain polite, but firm. Insist on your right to be included in all decisions.
6. Listen to your child. His/her point of view is paramount, and he/she is the real expert in this area.
7. Talk to other parents who have shared similar experiences.

The Physician

The Physician has both primary medical responsibility for the child and is key in the discharge planning process. Usually the child's doctor will first recognize the possibility of moving the child from hospital to community. Thus the Physician is actively involved during Phase I in determining a candidate for home care.

During Phase II, the Physician remains responsible for the child's overall medical care during development of the Discharge Plan. The Physician will usually have the most active role in identifying equipment and related medical needs to be included in the Discharge and Home Care Plans. The Physician must give medical approval to the plan prior to discharge. During Phase III, the Physician continues to assume responsibility for monitoring medical care.

The primary care Physician in the hospital will not necessarily be the doctor who eventually takes care of the child in the community. For example, the neonatologist--in conjunction with another hospital pediatrician--may be involved in the decision to send an infant home. In most instances, more than one physician will be involved. Hospital-based physicians or sub-specialists may have primary responsibility for in-hospital care in Phase I, while in Phase III a community-based physician may be responsible for the child's ongoing medical care. It is important that all of the physicians work together effectively in order to insure the effective Discharge and Home Care Plans.

The Care Manager

The Care Manager is a trained professional (usually a social worker) responsible for writing, coordinating, and implementing the Home Care Plan after the child's discharge. The coordination is all important to avoid duplication of efforts and service gaps in the Discharge or Home Care Plans. In Phase I (the determination of a candidate for home care), the Care Manager may be an inactive participant, but his/her knowledge of existing and potential community support systems and services may be essential in the determination of home care.

Once the child is a candidate for community-based care, the Care Manager's role increases during Phase II as he/she assumes the major responsibility for devising, coordinating, and implementing the Home Care Plan. The Care Manager may also assist in developing the Discharge Plan. With the child's Parents (or guardian), the Care Manager will insure that community support services are available and accessible.

During Phase III, the Care Manager's role diminishes after the child is at home. At this point, the chief task of the professional is to provide back-up support to the family or to be a temporary coordinator in cases of significant changes in the home setting.

GUIDELINES FOR CARE MANAGERS

1. See that parents are involved in every aspect of the decision-making process.
2. Make schedules of family life, before and after the placement of the child at home.
3. Help suggest actual daily living plans for the child after you have as much information as possible about the family and the child.
4. Remain "on top of" all community services.
5. Give copies of all written reports to parents. Explain the "jargon" contained in the reports.
6. Help the parent to know the child's strengths and abilities.
7. Become involved with the whole family to develop a general picture of needs.
8. Explain how to coordinate needs and services.
9. Listen!

*Some of the points mentioned in the guidelines were suggested by or adapted from Looking Forward: A Guide for Parents of Children with Disabilities, published by the Maryland State Planning Council on Developmental Disabilities, Copyright January 1980.

The Interdisciplinary Team

The **Interdisciplinary Team** includes all professionals from the various disciplines (medical, social services, nursing, speech and hearing, etc.) involved in the development and implementation of the **Home Care Plan.** This team may also include parents of other severely disabled children successfully moved to family care; these parents have developed applicable knowledge and skills. In fact, they are often the real "experts."

The various disciplines represented by the **Interdisciplinary Team** are necessary to the overall viability of the plan. One part of the **Interdisciplinary Team,** the nursing component, can give the most accurate information concerning required care, feeding, the activity level, or other vital information about the child. During Phase I, the team should participate in determining whether the child is a candidate for discharge to a less restrictive setting.

During Phase II, the **Interdisciplinary Team** members actively participate in the development of the **Discharge** and **Home Care Plans** and in the identification of community resources. The team should also be active in educating the parents or other care providers for the child's move home. During this phase, all arrangements must be made, all environmental changes to the home completed, funding sources confirmed, and the plan double-checked.

During Phase III, the **Interdisciplinary Team** provides as-needed support and assistance to the **Parents** as the latter assume the major responsibility for the care of the child.

Community Support Services

Community Support Services include all resources, vendors, and agencies with a role in supporting the family and insuring the child's adjustment within the family. Although these service providers are not actively involved during Phase I, the discharge team must take into account what resources are offered, available, accessible, or potentially developable within the community.

During Phase II, the **Care Manager**, the **Parents**, and the **Interdisciplinary Team** must: a) specify the needs of the child and the family; b) identify and arrange commitment of the **Community Support Services** for in-home care.

> PROVISIONS FOR COMMUNITY SUPPORT SERVICES AND FOR IDENTIFYING POTENTIAL PROBLEMS MUST BE MADE BEFORE THE CHILD GOES HOME

In Phase III, these **Community Support Services** become active participants in the actual delivery of services and continue as long as necessary. The degree of the child's disability and the impact the child will have upon the other members of the family should be fully discussed before the child comes home. Potential problems should be identified, and the family should be given every possible support in their adjustment to their new role. Too often, these important considerations are left to Phase III; sometimes it is then too late to avoid serious family disruption. A medical **Discharge Plan** and a **Home Care Plan** should be clearly in place before the child comes home. The **Parents** should clearly understand their role and expected functions before the child is home.

CHART OF PHASES, ROLES, AND ACTIVITIES

PARTICIPANT	ACTIVITY Acute Care to Stabilization Phase 1	Planning the Discharge and Home Care Phase 2	Implementing the Home Care Plan Phase 3
Parent Mother and/or father; legal guardian.	1. helps determine if child can come home; 2. evaluates and is evaluated on ability to give home care.	1. helps develop Home Care Plan; 2. requests training needed for Home Care Plan; 3. helps identify needed services and supports; 4. plans any necessary home modification. 5. charts time required for ordinary domestic activities before child comes home.	1. assumes major responsibility for care of child; 2. evaluates and requests additional needed services; 3. charts family activity after child comes home.
Physician Primary attending medical specialist--provides medical care in all phases.	1. recognizes possibility of moving child from hospital to community.	1. develops Discharge Plan; 2. identifies medicine, medical needs, and equipment necessary for home care; 3. develops Home Care Plan in conjunction with parent(s), care manager, and interdisciplinary team.	1. continues (in most cases) to provide medical care; 2. serves as consultant to parents, care manager, interdisciplinary team, and support services.
Care Manager Trained professional (usually a social worker) who devises, coordinates, and helps implement the Home Care Plan.	1. serves as consultant to parent(s) and physician about community support systems.	1. assumes overall responsibility for development of Home Care Plan; 2. can participate with physician in developing Discharge Plan. 3. works closely with parents and insures availability of community support services.	1. provides backup support to parents as they assume responsibility for care management; 2. is available for periodic trouble-shooting.
Interdisciplinary Team Professionals from all disciplines (medical, nursing, social services, speech and hearing, educational, and often other parents) whose expertise comes from experience.	1. serve as consultants about possibility of discharge to community. The hospital's nursing team provides information about level's of care, feeding, nutrition, and activity of the child.	1. participate in development of Discharge Plan and Home Care Plan; 2. help identify community resources; 3. educate parents to prepare for child's placement at home-- a. environmental changes b. confirmation of funding c. training.	1. serve as consultants as needed and provide ongoing support.
Community Support Services All resources, parent support groups, voluntary organizations, national organizations, vendors, and agencies insuring the child's adjustment to the home.		1. contacted by care manager, parents, or interdisciplinary team to check availability and provision of resources; 2. consulted in Discharge Plan and Home Care Plan.	1. deliver services.

BEST COPY AVAILABLE

SECTION III

PLANNING FOR DISCHARGE AND HOME

The Discharge Plan

The phases of progression from hospital to home have been defined; the roles of the pilots and planners have been delineated; now the plans must be formulated.

The child (in most cases) has been the resident of an acute-care facility for an extended period. When his/her condition becomes stabilized, the physician determines that home care is feasible. After the child has been moved from intensive care to a regular pediatric unit, the recognition of home care as the most effective and psychologically appropriate care leads to the development of a plan for future care.

The **Physician** and **Interdisciplinary Team** will develop an overall medical **Discharge Plan** during Phase II. This plan should detail all equipment needs, all prescribed medicine, and all needed supplies. It should clearly define the medical protocol to be followed at home. Additionally, the plan should include any alternative arrangements that might be necessary, such as with a local hospital to care for the child in a medical emergency, or with the discharging hospital for emergency return.

For some children, the plan will be brief; for others, it will be extensive. The details of the plan are the responsibility of the discharging hospital and require the approval of the physician in charge. The plan will indicate needed hours of nursing and training, both for nurses and parents, prior to the child's discharge.

State agencies such as specialized Maternal and Child Health programs and Crippled Children's programs may be developing and directing specialized state programs for these populations and would participate with the discharge team in the last phases of the plan in order to assure its feasibility. Assuring the availability of nursing service, specific training, home service and maintenance--all are examples of the participation of state agencies.

The Home Care Plan

As the **Physician** draws up the **Discharge Plan** in Phase II, the **Care Manager**--designated in this phase--is simultaneously drawing up the **Home Care Plan**. The Discharge Plan includes the medical aspects of needed services; the **Home Care Plan** includes the "nitty-gritty" to implement these services. The **Home Care Plan** is really a series of plans which includes the following elements:

a) Care Management Services:

The designated **Care Manager** should coordinate the services of other providers. These services and their providers should be described in the plan. The **Care Manager** will:

- help the family avoid duplication of services;
- assure that the child's needs can be met in the home;
- provide the family with information regarding alternatives in care choices, available services, and their rights as parents;
- initiate referrals cconsistent with the plan and acceptable to the needs of the family;
- act as an advocate for the family in negotiations to obtain necessary services as detailed in the plan.

(see pages 12 and 13)

b) Respite Care Services:

Attention should be given to providing for temporary residential, respite, and supportive services to assure that the child can remain in the community if the family requires temporary relief from care-giving responsibilities.

c) Home Modification:

For some children, changes in the home (such as additional electrical wiring, insulation, weatherproofing of the windows, construction of wheelchair ramps, etc.) may be necessary. Such environmental modifications should be detailed in the plan and **SHOULD BE COMPLETED LONG BEFORE THE CHILD'S DISCHARGE.** (see pages 14-16)

d) Nursing Services:

A detailed plan for nursing services should include hiring, training, and planning for reimbursement for nurses. This plan should be consistent with the Nursing Act for the state in which the child lives. The nursing staff should be familiar both with the overall medical **Discharge Plan** and the **Home Care Plan**.

e) Supplies and Equipment Plan:

Based upon the **Discharge Plan**, a section of the **Home Care Plan** should include methods of getting supplies and equipment and of replenishing them when needed. This part of the **Home Care Plan** should identify the vendor(s) and should be kept near the bed so that the person in charge can obtain additional equipment easily. (see page 17)

f) The Family Support Plan

Each family should have someone, either the **Care Manager** or a social worker, to share their concerns about the impact of the placement of their child in the home. The **Care Manager** should draw up a schedule of family activities both before and after the child comes home. Once these activities are charted and the differences are seen, some of the possible friction can be avoided by rescheduling activities and by taking into account the needs of all--child, parents, siblings, and the entire family unit. (see page 18)

g) The Family Finance Plan:

The **Home Care Plan** should give a detailed suggested financing plan for the family; the plan might recommend application to one or more of the following:

- Insurance companies;
- Community funds;
- Crippled Children's funds;
- Title XIX Medicaid and/or Title XIX Medicaid Waiver.

The **Care Manager** (or in some cases a member of the **Interdisciplinary Team**) should work out these funding suggestions to avoid any possibility of the family's loss of funds which enable the child to remain at home. Again, this aspect of the plan should be worked out **WELL IN ADVANCE OF THE CHILD'S DISCHARGE.**

In devising the financial plan, the **Care Manager** and the **Parents** should investigate the following resources:

1. Social Security (a part of the S.S. program is set aside for families with a disabled member).
2. Supplemental Security Income (S.S.I.) for Aged, Blind, and Disabled (S.S. program). Application can be made by a parent, guardian, or other responsible person for a disabled child or adult. The S.S. office makes the determination of eligibility for the program.

Family Finance Plan (continued)

3. Veteran's Administration. Financial aid for medical care is provided to a spouse or a child of a veteran (living or deceased) who has a permanent, total disability resulting from an injury during military service. Consult the V.A. for further details.
4. Medicaid programs. Consult the Department of Social Services in your local health department to determine elegibility.
5. Medicare programs. Primarily for families who receive S.S. benefits. Consult the Department of Social Services in your local health department to determine elegibility.
6. Other programs: Aid to Families with Dependent Children; Food Stamps; Nutrition Program for Women, Infants, and Children (WIC); Emergency Assistance Grants; Private Voluntary Agencies.

h) The Community Support Plan:

In most cases, many community agencies may play vital roles in making the entire plan successful. For example, if 24-hour nursing is needed, the highway department's cooperation may be necessary to insure that roads to the house are passable in bad weather. If electric power is needed for life-sustaining equipment, the power company should be aware of the family's vital need. These same principles apply to other emergency measures from local services and utilities (telephone, ambulance, etc.). Your key to success is stating politely and clearly your request before an emergency occurs. Included below are sample letters to the various companies as a guide to how information can be relayed to the companies. (see pages 19 and 20)

CONCLUSION

These plans give not only a profile of services needed, but of the family itself. Thus, the plan is actually a series of plans, each divided into a category. The **Care Plan** must take into account both the operating model of the family and the intellectual and emotional capacity for family and child adjustment to the home environment.

> The **Care Manager** must make the **Home Care Plan** fit the family, not the family fit the plan.

If the Care Manager tries to force the family into a plan, the plan could lead to disaster. Therefore, the more schematically the **Care Manager** can visualize the family operation, the more the likelihood of the plan's success. The family profile of behaviors, needs, and timing can help the **Care Manager** to suggest a plan which in constructive, not obstructive. The Care Manager works by suggestion and observation, rather than by command.

Office _____ Coordinator _____

Telephone _____

Other _____ Date _____

INITIAL CONTACT SUMMARY

Patient's Name _____ SSI# _____ DSCC# _____

Address _____ IDPA# _____ REC# _____

County _____ B.D. _____ Tel# _____

Guardian's Name _____ Address _____

Verify SSI _____ Verify IDPA _____ Verify Insurance _____

FAMILY

MEDICAL HISTORY
(According to Parents)

INVOLVED SERVICE PROVIDERS

SERVICES NEEDED
(Parents' perspective:
goals and expectations)

PLAN

SSI-DCP#9.3

NAME_____

SSI#_____DSCC#_____

City_____County_____

PROBLEM	REMEDIAL ACTIVITY	OBJECTIVES	PROVIDER/ PAYEE & DATE

SSI-DCP#11

PHYSICAL FACILITY CHECKLIST FOR THE HOME

HOSPTIAL_____ CITY_____ DATE_____
PATIENT'S NAME_____ HOSPITAL I.D.#_____
PREPARED BY_____ TITLE_____ TELEPHONE_____

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
I. Accessibility		
A. Physical facility must accomodate the child's specific disability (to include equipment necessary for facilitating mobility and/or transport) to provide access with single caretaker assistance.		
B. Where applicable, physical facility must not restrict delivery of large or heavy medical equipment		
II. Space Requirements		
A. Child's room must have minimum square footage area of 9 ft. X 9 ft.		
Note: Any living area in the house may be designated as the "child's room" (e.g., bedroom, dining room, recreation room).		
B. Storage		
1. Immediate access, e.g., night stand--used to store equipment/supplies with utilization frequency of 8 hrs. or less, e.g., suction catheters, suction machine, gloves, dropper bottle.		
2. Proximal access, e.g., closet--used to store equipment/supplies with utilization frequency of 24 hrs. or less, e.g., infant scale, water bottles, specimen cups, and immediate access items in larger quantities. Can include small volumes of oxygen replacement. The proximal access storage area must be in close proximity to the child's room.		
3. Bulk storage, e.g., basement or garage--must be large enough to accommodate 1 month's equipment/supplies and at least 1 week's oxygen supply.		
Storage areas must be free from excessive dampness. The temperature must not permit water to freeze. Storage areas must not contain toxic chemicals, e.g. cleaning solutions, fertilizer.		

PHYSICAL FACILITY CHECKLIST FOR THE HOME (continued)

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
III. Electricity Requirements		
A. A qualified electrician is required to evaluate the physical facility for ability to accommodate the child's electrical supply needs.		
B. The physical facility must be supplied by a minimum of 100 amp. electrical service.		
C. A minimum of two separate 15 amp. branch circuits must supply the child's room.		
D. If the main distribution panel utilizes fuses, four spare fuses of appropriate capacity are required to be stored near the fuse box.		
E. A minimum of four duplex electrical outlets on each of the two 15 amp. branch circuits is required for a total of eight duplex outlets in the child's room. Note: This is in addition to the usual and customary installation. Therefore, this requirement is not to be interpreted as the total number of outlets required for the child's room.		
IV. Special Equipment		
A. A telephone should be at the child's bedside.		
B. A mechanical whistle should be at the child's bedside.		
C. A battery-powered flourescent flood light should be at the child's bedside.		
D. Power failure alarm/light should be plugged into the same house electrical circuit as the ventilator.		
E. One smoke alarm and one five pound CO_2 fire extinguisher should be located on each level of the home (including the basement).		

PHYSICAL FACILITY CHECKLIST FOR THE HOME (continued)

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
V. Ventilation A. Ventilation must be adequate to permit safe recharging of wet cell marine type batteries.		
B. Oxygen storage areas must have adequate ventilation.		
VI. General The house must meet local safety, sanitation, and building requirements.		
VII. Other Considerations		

VIII. Summary of equipment/home modifications necessary for safe discharge home:

(This checklist was drawn up by the Children's Home Health Network of Illinois.)

DETERMINATION OF SERVICE/EQUIPMENT NEEDS FOR CARE MANAGERS AND PARENTS

Statement of Need	Reason for Need	Resource Required	How to Secure Resources		
			Who	When	Cost
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					

CHECKLIST OF RESOURCES TO ANSWER NEEDS

Resources of family: (ex.: mother is a teacher)	1.	
	2.	
	3.	
Resources of extended family: (ex.: aunt is a nurse)	1.	
	2.	
	3.	
	4.	
	5.	
Resources presently used: (ex.: assistance from church group for transportation)	1.	
	2.	
	3.	
	4.	
	5.	
		Methods of Identifying and Contact
Resources (above) to be expanded: (ex.: other churches in same denomination could supply transportation, respite care, etc.)	1.	1.
	2.	2.
	3.	3.
	4.	4.
	5.	5.
Other potential resources (ex.: parents of children with similar handicaps)	1.	1.
	2.	2.
	3.	3.
	4.	4.
	5.	5.
	6.	6.

Manager-Midwestern Power Company
132 Main Street
Indianapolis, Indiana 603__

October 26, 19__

Dear Sir:

My son has a rare and very serious disease called adrenoleukodystrophy. After his stay in the hospital for the last few months, the doctor has decided that he can come home. We are looking forward to bringing him home next Saturday.

I am writing this letter to let you know that John also has other complications requiring the regular use of life-support equipment which uses electricity. The social worker at the nospital suggested that I write to you and let you know of our acute need for electrical power. She said that you might be able to repair power lines and other equipment in our area more quickly if you were aware of such a medical need. We will have a battery back-up power source, but we will feel more comfortable knowing that your company is aware of the need for power in this home. Please feel free to call me, or perhaps I can stop by your office and discuss the situation in more detail. Our physician is Dr. Tom Smith; his phone number is (312) 345-76)2. Dr. Smith said that he would be very willing to discuss John's case in more detail if you feel it is necessary.

Thank you for your consideration of this matter which is very important to my family.

Very truly yours,

Susan Alexander

County Highway Department
132 West Jackson
Springfield, Illinois 60432

October 26, 19__

Dear Sir:

Local medical providers and Children's Hospital have arranged for the discharge of a severely disabled child whose life is being supported by a ventilator. Jim McBee will be moved from Children's Hospital to his own home on November 3, 19__. His care plan includes around-the-clock nursing service.

This letter is to request your cooperation in establishing a priority for keeping the roads open to 1223 West Washington Street. As you know, this house is approximately a mile from the edge of the city and in inclement weather has access problems. We would like to make every effort possible to assure that nurses can get to this home every eight hours.

We sincerely hope that the highway department will take this medical situation into consideration when establishing snow-removal priorities. Please feel free to contact either me or the family.

Thank you for your cooperation.

Very truly yours,

Paula Epstein
Medical Social Worker
Children's Hospital

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SAMPLE LETTERS

Ace Ambulance Company
1472 West Jefferson Street
Springfield, USA 12345

October 26, 19__

Dear Sir:

John Sarvis, an 8-year-old severely disabled child, is being discharged to his home on November 22, 19__. John's condition has stabilized in the last few months, and the medical team at Children's Hospital feels comfortable about discharging him to home care. There may, however, be a need for him to be taken to the local hospital in an emergency situation. We would like to notify your company of the location of the home (14 Maple Street at the corner of Oak Avenue) and the quickest way to get there in an emergency (Main Street north to Maple Street, turn left and proceed two blocks). Even though we do not anticipate such an emergency, please call me at (301) 123-8765 to discuss the situation in detail and to make all necessary arrangements.

Thank you for your cooperation.

Very truly yours,

Harriet Gage
Social Worker

Commissioner Harry Jones
Uptown Fire Department
19 Main Street
Grovers Corners, USA 10229

October 22, 19__

Dear Sir:

I am writing to inform you that Don Miller is being is being discharged from Beth Israel Hospital on November 20, 19__. Donald, who has a series of physical ailments, including bronchopulmonary dysplasia, will be residing at his parents' home at 24 Monroe Street here in Grovers Corners. He is dependent upon life-support equipment like a ventilator and suction machines. He is also scheduled to receive 24-hour daily nursing care. Episodic flare-ups may require emergency attention, even though the doctors at Beth Israel have determined that his conditon is quite stable. We are, therefore, making sure to give notice to your department in the event that Don may someday need emergency care best provided by the Rescue Emergency Squad of the Fire Department. Also, in case of fire, it would be difficult to move Donald. Therefore, we are requesting your advice, and would welcome further conversations about this matter. If someone from the Fire Department feels that a visit to the home would be helpful, please call me at (415) 337-3842.

Thank you for your cooperation.

Sincerely,

Susan Green
Social Worker

SECTION IV

ORGANIZATIONAL SYSTEM OF COMMUNITY RESOURCES

Incredible stories abound about families trying to meet their child's needs through involvement with a large number of health and social service agencies and having many needs go unmet. These tales include competing agencies, duplication of services, and a lack of knowledge on the part of many agencies about the functions and roles of other agencies.

A well-developed program for organizing support services for handicapped children and their family should include an educational and supportive component. The family could then become their own advocates.

In a number of states, state Maternal and Child Health programs, Crippled Children Services programs, special education programs, or others are actively attempting to organize community resources for these children. Ask the **Care Manager** assigned to your child to help you to familiarize yourself with the programs in your own state. Each state has a different system of agencies and regulations, and the Care Manager will assist you in your exploration and discovery of community resources.

The task of this workbook is to suggest methods for constructing a system for parents and designated **Care Managers** to enhance their ability to optimize the environment in which the child and family live.

The Systems Approach

Define the Need

The medical needs of the child should be prescribed by the child's primary care physician and listed in both the **Discharge and Home Care Plans.** The other needs of the child and family should be established by the **Care Manager** and included in the child's **Home Care Plan.** The family and **Care Manager** should list the child's unmet needs and then develop a plan with the broader **Interdisciplinary Team** to meet those needs. Otherwise, the family might waste time requesting inappropriate items or services, or might request duplicate services.

Identify the Appropriate Resource

1. Ask the social worker at your local hospital or your pediatrician for referrals to a national organization dedicated to the disability of your child; ask also for their local office; inquire about the scope of their services.
2. Ask your clergyman for resource referral.
3. Ask another parent of a similarly disabled child about local organizations for parents; attend their meetings; request their literature.
4. Make an appointment in the school system with your local special education director, teacher, or other allied personnel concerning your child's needs.
5. Call the local coordinating council for handicapped or disabled children if one exists in your area.
6. Consult your telephone book for statewide Crippled Children and other specialized programs to which your child may apply. Call your local Social Security office and inquire about your child's eligibility for SSI.

Your participation in the evaluation process should be the participation of a peer with other professionals. If, in your opinion, a professional discounts your input or excludes you from the overall process because you are "only a parent," request another professional. Remember that you are an equal, but you must speak up if your opinions and words are to be recorded and your advice is to be acted upon.

Based upon changes in the child's development, treatment plans need to be continually reassessed. Successful, reputable agencies and special education programs will conduct frequent staff meetings to reexamine the original goals and make changes in the child's plan as necessary. Remember also that public schools are required, under the provisions of Public Law 94-142, to review your child's Individualized Educational Program at least once a year. You should feel free at all times to request a reevaluation.

The wealth of information and possiblities can have its drawbacks. Families of disabled individuals are often overwhelmed by the number and complexity of individuals, agencies, and service organizations. Recently in the Midwest, over 25 agencies and 47 individuals were involved in the delivery of services to a moderately disabled child and his family. Too much assistance can be detrimental. Unrecognized and unmet needs might result from the abundance and the total situation might become close to chaotic. The task is best accomplished if one person with an appropriate supportive team defines the needs of the child and the family, and then develops a plan for meeting those needs. Contacts with the family, community resources, agencies, and other individuals should be the responsibility of one individual, and not all of the involved people. One member of the family will eventually become the **Care Manager**, and he/she--as did the original **Care Manager**--will be responsible for insuring all needed services without duplication.

A well-developed program for organizing support services for handicapped children and their family should include an educational and supportive component. This program would ultimately allow the family to become their own advocates. By mobilizing their resources to call for improvements in resources, the family can more effectively meet the needs of the child.

Readers of this workbook should also consult Power-Brokering in the Community, one of the companion books in this series.

Understanding the Approach

Many community voluntary health chapters have prescribed available areas of service. Often, you must seek them; these groups will not necessarily come to you and your disabled child.

Parent support groups are beginning to spring up all over the nation. These groups are very valuable to parents and others involved with planning and care management for disabled and handicapped children. Such groups are often able to provide more than support by actually imparting information to new parents, speaking before groups, representing the cause before legislators, explaining the burdens to state and other public officials, and in effect, forming an advocacy group for children. Such groups are usually staffed by parents and are extremely valuable in helping other parents work through their emotional and functional difficulties.

National foundations and health chapters have proved themselves as valuable resources in meeting unusual and well-defined needs. For the best response from a foundation, make sure your case is adequately presented to them. A very useful source of identifying these agencies is A National List of Voluntary Organizations in Medical Genetics and Maternal and Child Health, available from the National Center for Education in Maternal and Child Health, 3520 Prospect Street, Washington, DC 20057. Many states have homemaker and nursing services provided for by either that state's child welfare or public welfare agencies. The social worker at your local hospital or a clergyman should be able to tell you if such resources exist in your community.

A "court of last resort" for concerned parents is to explain their situation and their needs to their state representative or congressman. Groups are more usually more successful than individuals in bringing a legitimate need to a legislator and will usually receive an understanding hearing. This hearing will often result in a service or activity to alleviate the problem area.

The discovery of additional resources will probably proliferate from the resources known to the individuals of the **Interdisciplinary Team.** The wise **Care Manager** will bring all unusual and unmet needs to this group.

The Future

Only a few years ago, many of the severely medically involved and disabled children would not have survived. Many of these children are still relatively young and our collective experience with them as teenagers, young adults, and adults, is extremely limited. The limits of their potential remain unknown.

As we begin to look at this group, we must recognize that not all such children have parents with the parenting ability, stamina, interest, coping power, capacity, or support systems necessary to provide an in-home setting for their children. It is, of course, critical during **Phase** I when the medical team is considering if a child is a candidate for in-home care, to assess carefully the child's parent as a potential resource. In cases when the parent is not available, what is the future of the child? Is the child

to be committed to long-term care in a medical facility, or do we have a responsibility to search for a substitute home environment within the child's extended family, or through the development of a highly specialized medical foster home? With commitment of the medical community to in-home care comes the alternative need for highly specialized medical foster-family homes. To move in this direction, specific standards for these homes must be developed, either nationally or individually by state. In most states, existing standards for foster family care can be used to develop the required specialized standards. Additionally, intensive training and preparation of the non-parent caretaker will be an essential aspect of providing for the severely disabled child.

Foster-family or relative homes may be augmented by community development of specialized medical group home settings to serve some severely medically involved children. To preserve the family atmosphere of such group homes, the number of disabled children in any one home must be limited. Cost-effectiveness factors are a consideration in communities large enough to support this kind of resource. Perhaps, for example, one nurse could provide care to two or more children at one time; less emergency equipment may be necessary; less inventory of parts for equipment repair may be needed.

Public awareness and education are other challenges as more and more severely handicapped children leave hospital settings for family/community care. We must look to the future to the kinds of care and the needs of these individuals as adults. Some may be able to live fairly independently; some may require a type of sheltered/supportive living arrangement; others may require more intensive care in family or group home settings.

Parent support groups are a viable, necessary link in the community support system. Probably no one can better help the parents of a child just diagnosed as having a severely disabling medical condition than another parent who has already gone through the experience. Parent support groups can provide a number of services: assisting individual families; serving as members of the Discharge Team; providing public education and awareness campaigns; working with social agencies and others to recruit, train, and prepare foster families; serving as community advocates for the educational, recreational, and social needs; lobbying for funds to make in-home care possible.

Finally, it is the responsibility of all of those committed to piloting the children on the journey from hospital to community to identify the road-blocks--financial, social, communal, attitudinal--and to seek effective ways to remove these barriers. We are just at the beginning. As we move ahead, we find unanticipated barriers and blocks which must not stand in the way of any child who is a candidate for community-based care.

The trip might be perilous, but we will rise with the road to meet its challenges. Each journey begins with but a single step, and this journey is a necessary one. It is only the first step which is difficult.

SPECIAL NOTE: To the Parents of Children Between the Ages of 0-3

While some states may lack active programs for children between birth and three years, many are now developing early intervention programs specifically created for early identification of developmental problems in children. If you feel your child has a noticeable problem or handicap, or seems to be falling behind other children in specific developmental tasks such as walking, talking, hearing, or controlling intensity of activity, you may want to call your public health nurse or your local special education program about information on early intervention programs. One of the advantages of participating in these programs will be the contact with other parents experiencing similar thoughts, anxieties, and questions.

Depending upon your state and the size of your community, there are various establishments (including health agencies, hospitals, university child development centers, private and public schools) with specialized early intervention programs to meet the needs of your child. Your aggressive and persistent efforts--coupled with those of your **Care Manager**--will pay off for your child. In almost every American community is a network of people dedicated to serving those with special needs. Your participation will give you the opportunity to bring to them needed information while you receive from them encouragement and support.

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